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Operationalising routinely collected patient data in research to further the pursuit of social justice and health equity: a team-based scoping review

Katie Chadd^{1*}, Anna Caute¹, Anna Pettican¹ and Pam Enderby²

Abstract

Background Vast volumes of routinely collected data (RCD) about patients are collated by health professionals. Leveraging this data – a form of real-world data - can be valuable for quality improvement and contributing to the evidence-base to inform practice. Examining routine data may be especially useful for examining issues related to social justice such as health inequities. However, little is known about the extent to which RCD is utilised in health fields and published for wider dissemination.

Objectives The objective of this scoping review is to document the peer-reviewed published research in allied health fields which utilise RCD and evaluate the extent to which these studies have addressed issues pertaining to social justice.

Methods An enhanced version of the Arksey and O'Malley's framework, put forth by Westphalm et al. guided the scoping review. A comprehensive literature search of three databases identified 1584 articles. Application of inclusion and exclusion criteria was piloted on 5% of the papers by three researchers. All titles and abstracts were screened independently by 2 team members, as were full texts. A data charting framework, developed to address the research questions, was piloted by three researchers with data extraction being completed by the lead researcher. A sample of papers were independently charted by a second researcher for reliability checking.

Results One hundred and ninety papers were included in the review. The literature was diverse in terms of the professions that were represented: physiotherapy (33.7%) and psychology/mental health professions (15.8%) predominated. Many studies were first authored by clinicians (44.2%), often with clinical-academic teams. Some (33.25%) directly referenced the use of their studies to examine translation of research to practice. Few studies (14.2%) specifically tackled issues pertaining to social justice, though many collected variables that could have been utilised for this purpose.

Conclusion Studies operationalising RCD can meaningfully address research to practice gaps and provide new evidence about issues related to social justice. However, RCD is underutilised for these purposes. Given that vast volumes of relevant data are routinely collected, more needs to be done to leverage it, which would be supported by greater acknowledgement of the value of RCD studies.

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Keywords Routinely collected data, Real world data, Big data, Social justice, Health inequalities, Allied health professions

Introduction

The contemporary capabilities of digital health infrastructures create enormous potential for scrutinising health care practices and treatments by analysing real-time, real-world data (RWD) to create real-world evidence (RWE) [1]. RWD most typically refers to information collected outside of traditional research studies, with RWE coined to refer to the evidence produced from its analysis [1]. Methodological approaches which tap into RWD sources offer an alternative understanding of ‘what works’ in practice, which can supplement evidence obtained through traditional approaches such as clinical trials [2]. The potential of analysing health data obtained outside of trials has been recognised by major stakeholders globally including the World Health Organization [3], the Food and Drug Administration [4] as well as the National Institute of Health and Care Excellence [5] in the United Kingdom. Nevertheless, RWD and RWE research is not without risks or challenges, and its observational nature, through the traditional lens of the research hierarchy in mainstream health and medicine research, often means it is sidelined and critiqued in favour of the rigour provided within a clinical trial [6].

Routinely collected data (RCD) describes data about patients that is documented routinely in clinical practice, typically in electronic medical records and registries [7], and is a vast source of RWD. Historically, RCD been associated with either being used by insurance providers using claims databases to make decisions about treatment options they will or will not cover [8] or individual care providers’ to run local service evaluations or audits, to drive quality improvement [9]. Such investigations therefore may not always be reported as *research*, be recognised with any value beyond their immediate means or have the chance to be published. This means their findings traditionally lack visibility, although the scholarly tide is beginning to change. Notably, through the COVID-19 pandemic, RCD was fundamental in the production of timely evidence regarding symptoms and treatment effects across sizeable cohorts which could inform public health policy [10]. RWD studies, including those based on RCD, are increasingly observed in the literature, alongside the acceleration of artificial-intelligence (AI) methods of analysis, and are being utilised as an opportunity to provide methodological enhancements, or substitutions in clinical trials [11–13].

Conducting analyses using RCD may also offer practising clinicians opportunities to interrogate their practice

and lead research that has direct relevance to their daily services and address pertinent research-to-practice gaps. While recent shifts have been seen, in the UK especially, to value clinicians’ priorities for what health research is needed [14], challenges remain for non-medical and non-nursing staff (referred to herein as *allied health professionals*) to actually carry it out [15–17]. By minimising time and resource constraints through conducting analyses of already-collected data, available at a clinician’s fingertips, it is possible that clinician-led research may be maximised. This offers allied health professionals - who are often disadvantaged in their capacity to conduct research compared with medics and nurses [16, 18] - an opportunity to engage in research. However, the extent to which RWD studies using RCD in allied health fields are being conducted is unknown.

Beyond this, RWD studies using RCD can expose, and monitor changes in, social injustices created by healthcare systems, and are well placed for “*asking tough research questions that focus on dismantling racism*” [19, p. 724]. That is to say that harnessing patient data through RCD analysis can investigate inequities and disparities in access to and outcomes from healthcare. Moreover, such evidence can be used to ask *why* they exist and tackle pertinent barriers to social justice, which describes “*full participation in society... resulting in equitable living and a just ordering of society*” [20, p.955]. When good quality data is routinely collected about the social identities, social strata and/or likely marginalisation of an individual within their given context, alongside information about their health care access and outcomes, rich analyses exploring interactions of and equity across societal factors and health are possible [21, 22]. Taking a social justice lens to leveraging RCD also offers an alternative avenue to knowledge production which partly address the valid and historical reluctance of marginalised populations to participate in traditional research studies [23, 24]. It should however be noted that by the nature of the data, samples would be restricted only to individuals already accessing healthcare, thus RCD analyses are prone to risk of “*data absenteeism*” [25]. People such as those who are living without a fixed address, or gypsy, traveller and Roma communities may be especially vulnerable to this, and *absenteeism* should be attended to in any study. Furthermore, the value of RCD is inextricably dependent on good quality data that is consistently collected, specific to the cause, and valid and reliable, which can often be a challenge [26].

Studies utilising RCD have several advantages over conventional trials. Firstly, they can utilise non-selected samples, meaning that the whole population receiving healthcare can be included and studied. This signals a major departure from the problematic consequences of conventional research approaches which historically fail to recruit diverse samples from their populations (even when the populations are highly diverse), as mentioned previously [27–30]. Fundamentally, this has resulted in the production of an evidence-base for clinical practice that is skewed towards benefiting the already-privileged population (notably, White people living in Western contexts) and thus represents one factor (though there are many, see Powell et al. for discussion in the UK [31]) that contributes to systemic injustices and inequities in health. A second advantage of using RCD to improve the evidence-base is there is an enhanced capacity for intersectional analyses through the systematic collection and linkage of large-scale patient data. This describes the capability of interrogating data using multiple levels to explore differences and associations between health metrics and compounding levels of disadvantage based on one's multiple intersecting identities [32, 33]. Whilst the potential of intersectional analysis to help address issues such as health inequalities is noted [34], the extent to which this is applied to RCD in the allied health fields is not known.

A search on PROSPERO and the JBI systematic review register for ongoing and intended systematic reviews on the topic was conducted, which identified there were no similar reviews exploring the key components of allied health, RCD and social justice. A literature search of key databases similarly indicated no other literature reviews which address the nexus of these topics. However, we did find several examples of scoping and systematic reviews exploring RWD for specific diseases related to allied health [35–37] and literature exploring social justice and allied health [38, 39]. But, we did not find research bridging these aspects to form a methodological perspective across professions. Existing reviews that bring together RWD and social justice are infrequent, and are limited to a clinical area (for example, on emergency care [40] or psychiatry [41]). An exception to this is a recent scoping review by Moorthrie et al. [21] who analysed RWD studies exploring health inequalities from diverse clinical areas. However their scoping exercise was relatively narrow, by including only studies which explicitly referred to improvements to data quality in relation to health inequalities. Therefore, to date, there is no comprehensive review of RWD studies in a broader sense that seeks to explicate their relevance to social justice, in order to understand the potential of operationalising data in this way.

To develop a greater understanding of the potential for RWD and RCD studies to foster this aspiration, it is helpful to conduct a scoping review to ascertain and map what already exists in the literature [42]. This scoping review signals as a departure point from the current rhetoric regarding health research and RWD on two fronts:

1. By validating RCD studies as sources of valuable evidence that can contribute to various health fields.
2. By positioning RCD studies as a fundamental approach for interrogating and dismantling injustices in healthcare treatments and services.

Drawing on the transformative research paradigm, guided by the transformative checklist [43], we outline a scoping review which aimed to:

- Document the use of RCD research in allied health fields in the published peer-reviewed literature.
- Describe the researcher team (clinician or academic), aims of studies, data sources and methods used in these studies.
- Evaluate the extent to which RCD research has aimed to address issues pertaining to social justice, specifically to document reference to:
 - tackling issues of health inequity.
 - inclusion of typically underserved populations in their samples.
 - intersectional analyses.
- Use the findings to create recommendations for future real-world data studies to advance the evidence base and particularly further the pursuit of social justice in health.

Methods

A draft a priori protocol was uploaded onto the Open Science Framework (OSF) platform for the purposes of a consultation period [44]. The consultation was open from 02 November to 07 December 2023, and participation was encouraged through social media and via the researchers' personal contacts. Comments and feedback were invited to be directly shared with the lead author, and the protocol was revised accordingly. The full protocol was published in 2024 [45] and is summarised here for convenience. Arksey and O'Malley's methodological framework [46] was utilised to guide this scoping review, which also incorporated recommendations from Westphalm et al. to 'enhance' this process and utilise a team-based approach [47]. Operationalising 'team-based' meant developing and applying a framework to aid the selection and invitation of collaborators based on

specific clinical and research expertise “into the method” (p5) [47], as reported in our protocol [45]. Whilst guided methodologically by these, our review is reported in line with the PRISMA Extension for Scoping Reviews (PRISMA-ScR) guidance [48].

Stage 1) Specify the research question

The Sample, Phenomenon of Interest, Design, Evaluation, Research type (“SPIDER”) framework guided the development of the research questions which explore qualitative and quantitative aspects of studies [49, 50], leading to the identification of the following components:

- Sample: Peer-reviewed studies that have used RCD in non-medical, non-nursing health (*allied health*) fields.
- Phenomenon of Interest: How RCD has been used, by whom, and whether it addresses issues related to social justice (health inequities, inequalities, inclusive sampling and intersectional analysis).
- Design: studies of any design using RCD besides those utilising data collected as part of a clinical trial (i.e. outside routine care).
- Evaluation: The volume of research published and the extent to which it addresses our phenomena of interest.
- Research type: Primary research adopting any methodology.

The research question guiding this review is: “What research has been published in allied health fields that utilises RCD as its primary method, and to what extent does it address key issues pertaining to social justice?”

Stage 2) Identify the relevant literature

Eligibility criteria

Guided by the SPIDER framework, the eligibility criteria were that studies were peer-reviewed full-text papers related to allied health fields published at any time, and available in a language accessible to the research team (limited to English) (S-sample). This was to ensure maximal coverage, but limit results with insufficient data to evaluate to meet the aims of the review (such as conference proceedings which may not include detail on data sources, for example). Eligible studies were those demonstrating application of RCD (PI- phenomenon of interest), of any type of primary research (R-research) excluding studies utilising RCD collected through clinical trials (D-design).

Information sources

Searches were conducted in three health and medical electronic databases (MEDLINE Ultimate, CINAHL Ultimate and PubMed) which are presented and rationalised

in the protocol. No other strategy was adopted (e.g. citation chasing or snowballing) nor was grey literature searched due to the volume and breadth of retrieved articles in trial searches [45]. CINAHL Ultimate and MEDLINE Ultimate databases were harnessed via using EBSCOHost. A separate (but identical) search was run on PubMed. The final searches were conducted on 22 January 2024.

Search strategy

Table 1 shows the search strategy entered and limiters applied for the searches in both search platforms which is also explained further in the protocol [45].

Stage 3) Select studies

Selection of sources of evidence

Inclusion and exclusion criteria were developed based on the research question and search strategy, to guide the screening process. The criteria were first piloted by three researchers (KC, AP and AC) collectively, on the same 5% of articles to assess reliability, and reach consensus on where additions or changes to the inclusion/exclusion criteria were required to facilitate the screening process and bolster reliability. Following this, titles and abstracts were screened by 2 screeners independently (KC screened 100% and AP and AC screened 50% each). Again, the inclusion and exclusion criteria were discussed at interim points where clarifications were needed, and minor modifications were made as necessary. The final version of the inclusion and exclusion criteria are provided in Table 2. Full-text reviews for eligibility were conducted by two researchers (KC screened 100% and AP and AC screened 50% each which, where possible, were allocated based on expertise).

Stage 4) Extracting, mapping and charting the data

Data charting process

The data charting framework was initially piloted on five papers by three members of the team (AC, AP, KC) providing an initial opportunity for it to be refined if needed. A random 30% sample of the papers were then charted in line with this, by a first researcher (KC) and a second researcher (AP and AC looking at 15% each). This was to ensure a consistent approach was being taken and provide an opportunity for further modifications to the charting framework should they be required. The first researcher (KC) subsequently completed extraction of all the remaining papers.

Data items

Some data items were extracted automatically by Rayyan software (i.e. authors, title, year, journal). The data charting framework ensured capture of the remaining items

Table 1 Search strategy

Database	Search string	Limiters/expanders
PubMed	((("Routine data"[Title] OR "routine clinical data"[Title] OR "routinely collected"[Title] OR "routine clinical data"[Title] OR "real world data"[Title] OR "real world evidence"[Title] OR "electronic health"[Title] OR "medical records"[Title] OR "health record"[Title] OR "patient record"[Title] OR "patient data"[Title] OR ("registry"[Title] NOT "trials registry"[Title]) OR "service data"[Title] OR "service evaluation"[Title] OR "audit"[Title] OR "case note"[Title] OR "case notes"[Title]) AND (((("speech"[Title/Abstract] OR "language"[Title/Abstract] OR "occupational"[Title/Abstract] OR "physical"[Title/Abstract] OR "physio"[Title/Abstract]) AND ("therap*"[Title/Abstract] OR "patholog*"[Title/Abstract])) OR "physiotherap*"[Title/Abstract] OR "psycholog*"[Title/Abstract] OR "radiography"[Title/Abstract] OR "radiographer*"[Title/Abstract] OR "paramedic*"[Title/Abstract] OR "biomedical scientist"[Title/Abstract])) NOT ("systematic review"[Title] OR "meta*"[Title] OR "trial"[Title] OR "survey"[Title])) NOT (Interview*[Title/Abstract] OR "focus group"[Title/Abstract] OR "focus groups"[Title/Abstract])	Limiters: English language
EBSCOHost (for CINAHL and MEDLINE)	TI ("Routine data" OR "routine clinical data" OR "routinely collected" OR "routine clinical data" OR "real world data" OR "real world evidence" OR "electronic health" OR "medical records" OR "health record" OR "patient record" OR "patient data" OR ("registry" NOT "trials registry") OR "service data" OR "service evaluation" OR "audit" OR "case note" OR "case notes") AND AB (((speech OR language OR occupational OR physical OR physio) AND (therap* OR patholog*)) OR physiotherap* OR psycholog* OR radiography OR Radiographer* OR paramedic* OR "biomedical scientist") NOT TI ("systematic review" OR meta* OR trial OR survey) NOT AB (Interview* OR "focus group" OR "focus groups")	Limiters - Peer Reviewed; Research Article; Publication Type: Academic Journal Expanders - Apply equivalent subjects Search modes - Boolean/Phrase

Table 1 Search strategy applied to search CINAHL, MEDLINE Ultimate and PubMed databases

to both describe the nature of the research and address specific elements central to the research questions. To achieve the latter, we sought to be guided by existing frameworks related to RCD and health equity. Variables extracted from ‘The Reporting of studies Conducted using Observational Routinely-collected health Data (RECORD)’ statement [51] and the ‘NHS CORE20PLUS’ approach which describes a range of population groups likely to experience health inequality were used to guide this section of the data framework [52].

Ultimately, this included the following data items: Title of study, authors, journal of publication, year of publication, Country of first author’s institution, first author’s institution (clinical, academic or mixed), clinical and academic composition of the research team, health profession or area of focus, number of datasets used, reference to translating evidence to practice, rationale for study, objective, setting, participants, data sources, methodological approach (qualitative, quantitative, mixed). To address social justice aspects, the following were extracted and mapped as ‘central’ (i.e. a study with a stated aim to address an element of social justice), ‘secondary’ (i.e. a study which had a different primary aim or objective, but still explored an element of social justice as a secondary research aim or objective) or ‘mention’ (i.e. a study which did not explicitly intend to address issues

of social justice but nonetheless reported on them): presence of aim pertaining to any facet of social justice, presence of explicit aim pertaining to health inequalities or inequities, presence of aim to include underrepresented populations, presence of aim to undertake intersectional analyses.

Stage 5) Summarise, synthesize and report the results

Synthesis of results

Data was compiled in an Excel spreadsheet comprising the charting framework (as columns) and study information (as rows) to produce a summary table. Quantitative (categorical) data was analysed descriptively through producing basic pivot charts and analysing frequencies (for example, how many studies represented each professional area of practice). Appropriate measures of central tendencies were calculated for the number of datasets used. For qualitative aspects (such as describing the rationale, objective or how the studies addressed components of social justice), summary information recorded was imported into NVivo and analysed inductively by assigning codes at the phrase-level, to create a coding framework used to identify themes. An initial draft report of the results was shared via OSF for consultation between 11 October 2024–18 October 2024, prior to the full analysis and write up in line with the protocol,

Table 2 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<p>Study designs which clearly indicate use of routine clinical (patient) data, either prospectively or retrospectively, so long as the studies are exploring clinical or service-related questions (i.e. data collected in the everyday running of services)</p>	<p>Studies using non-routine data or are very unclear about the data obtained, which encompasses:</p> <ul style="list-style-type: none"> • Studies using specialised apps or tracking software to collate data that would not otherwise typically be collected in clinical services • Studies using surveys or interviews • Observational studies using other forms of data • Studies using data collected through clinical trials (including in nested forms). <p>Studies which use or explore routine data but not for the direct purposes of generating new information relevant to practice, which encompasses:</p> <ul style="list-style-type: none"> • Studies exploring methodological approaches to analysing routinely collected data (e.g. utilising AI or machine learning) UNLESS a clinical question was also addressed which used the data that was collected/analysed • Studies exploring new approach to collecting routine data (e.g. new databases or data collection tools UNLESS a clinical question was also addressed which used the data that was collected. • Studies exploring perspectives on collecting patient data, using routine-data for research or similar
<p>Studies that primarily concern the selected professions (physiotherapists, occupational therapists, radiographers, paramedics, practitioner psychologists, biomedical scientists and speech and language therapists), which also encompasses:</p> <ul style="list-style-type: none"> • Studies which heavily discuss recommendations for the selected professions, who are stated • Studies which explicitly relate to clinical areas or topics where the involvement of the selected professionals' is <i>strongly</i> implied. Examples of the latter include: <i>rehabilitation, falls, mental health services / professions / clinicians</i> 	<p>Studies that do not explicitly relate to the professions listed, which also encompasses:</p> <ul style="list-style-type: none"> • Studies where reference to the included professionals is limited or not a core part of the study e.g. studies that refer to anxiety levels or mental health diagnoses without referring to psychologists, studies that refer to physical activity without referring to physiotherapist, studies that refer to professions briefly as a 'future recommendation' or given as a minority mention in the context of a multi-disciplinary team. • Studies which only report on diagnoses or symptoms without referring to any of the listed professionals who make diagnoses or measure symptoms, or the professionals who may treat them • Studies that relate to dental x-rays which are not performed by radiotherapists.
<p>Studies that are empirical research studies</p>	<p>Studies which are:</p> <ul style="list-style-type: none"> • Study protocols • Literature reviews, including systematic reviews and meta-analyses • Discussion papers • Commentaries • Conference proceedings or poster abstracts
<p>Studies which are peer-reviewed journal articles which are either written in English or translated to English.</p>	<p>Non peer-reviewed articles Written in languages other than English with no translated version available</p>
<p>Studies where full-texts are retrievable</p>	<p>Studies where no full texts can be retrieved by the existing institutional subscriptions</p>

Table 2 Inclusion and exclusion criteria developed iteratively through screening and implemented in the scoping review

though no comments or feedback were received and thus no changes made in response to the consultation [44, 45].

Results

Selection and characteristics of sources of evidence

The initial search led to the retrieval of 1584 studies for title/abstract screening against the inclusion and exclusion criteria. The initial agreement rate for title/abstract screening was 86%, leaving 200 conflicts which were resolved by a third screener, resulting in 267 full-text papers being sought for retrieval and assessed for eligibility. Full texts were also screened for eligibility by two screeners, with an initial agreement rate of 82%. After disagreements were resolved, 190 papers were identified

as being eligible for inclusion in the review. Papers were excluded for several reasons including not utilising RCD or involving a profession or clinical area that was out of scope. Figure 1 provides the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart outlining the search and screening process [53].

Overview of studies

The data charting framework was considered accurate and comprehensive. Minor adjustments to wording were made through the initial pilot on 5 articles, which was followed by the obtaining of a 100% agreement rate in the extraction of data from a random sample of 55 studies

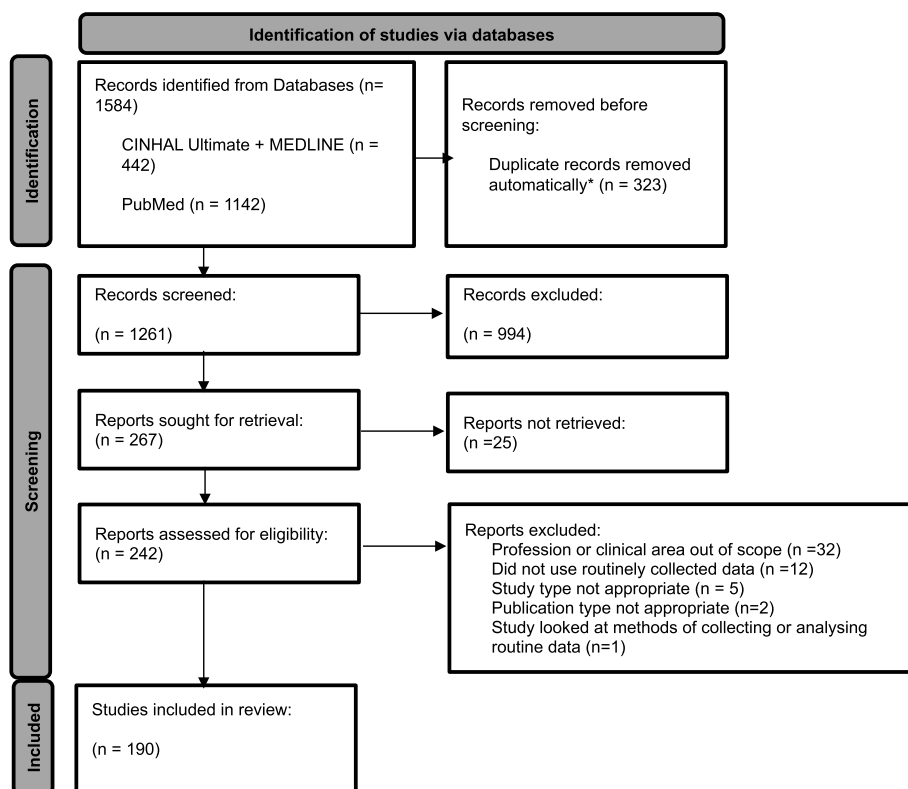


Fig. 1 PRISMA flowchart. Adapted from the PRISMA 2020 flow diagram for new systematic reviews to demonstrate results from database searches and screening procedures

(29%) which were analysed by 2 members of the research team.

The 190 studies included in this analysis was published by authors in institutions across 40 nations, though studies with first authors based in English institutions comprised 42.6% of these ($n=81$). Studies were associated with a range of allied health fields selected for this review, though over a third of the studies were related to physiotherapy ($n=64$, 33.7%) and 30 (15.8%) related to psychology / mental health. There were fewer studies on paramedical sciences ($n=17$, 9.0%) and even fewer associated with speech and language therapy ($n=15$, 7.9%), occupational therapy ($n=15$, 7.9%), and radiography /radiotherapy ($n=11$, 5.8%). Only 1 (0.5%) study was retrieved which related to biomedical sciences. The remainder of the studies ($n=37$, 19.5%) were relevant to a mix of professions or clinical areas with a range of professions at stake, most noticeably this related to stroke rehabilitation ($n=11$), accounting for 29.7% of this subgroup. Table 3 summarises this and provides reference to the corresponding studies.

First authors were mostly from clinical institutions ($n=84$, 44.2%) though there was a substantial proportion of academic first-authors ($n=57$, 30.0%), and

where studies were authored by more than one person, most research teams comprised both ($n=115$, 60.5%). Although, team compositions varied from purely clinical ($n=35$, 18.4%), purely academic ($n=18$, $n=9.47\%$), professional society-led ($n=3$, 1.6%) or a mixture of academic and professional societies, academic and industry, academic and charitable organisations, or charitable organisations and clinicians (collectively, $n=6$, 3.2%).

A third of studies ($n=63$, 33.2%) explicitly situated their RCD study in the context of a research to practice or research translation gap, however many did not directly do this ($n=69$, 36.3%) or only partially had this notion ($n=57$, 30.0%). Three major themes and 8 sub-themes (arising from codes) were identified relating to what the studies aimed to achieve. These were: *quality*(*quality of practice, quality of record keeping, access to and utilisation of services and quality of provision*); *patient factors*(*profiling a cohort of patients, evaluating the utility of a prognostic, diagnostic tool, assessment or indicator or identifying risk*); and *intervention* (*describing treatments and evaluating outcomes*). Some studies addressed multiple aims represented across these themes (see Fig. 2).

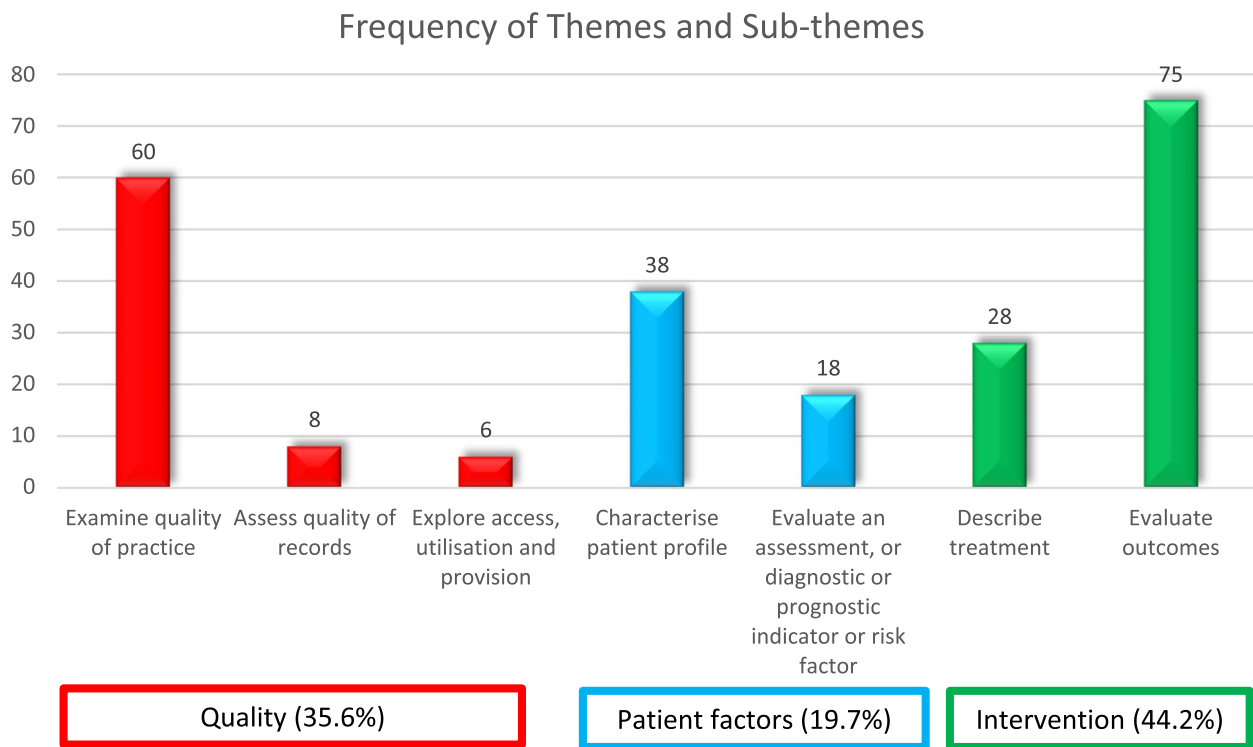


Fig. 2 Bar chart illustrating thematic analysis of the aims of the included studies, illustrating the frequency of themes (bottom boxes) and sub-themes (bars)

Table 3 Summary table of studies and professional or clinical areas

Professional or clinical area	n	%	References
Physiotherapy	64	33.7%	[54–117]
Psychology/ mental health	30	15.8%	[118–147]
Paramedical science	17	8.9%	[148–164]
Speech and language therapy	15	7.9%	[165–179]
Occupational therapy	15	7.9%	[180–194]
Radiography/Radiotherapy	11	5.8%	[195–205]
Biomedical sciences	1	0.5%	[206]
Mixed- stroke rehabilitation	11	5.8%	[207–217]
Mixed- other area or combination	26	13.7%	[218–243]
Grand Total	190	100.0%	

Table 3 Proportion of studies relevant to each profession or clinical area. ‘Mixed-other or combination’ includes studies with combinations of the professions (e.g. speech and language therapy and psychology/mental health) or clinical areas considered to span across professions where they may not be explicitly stated (e.g. pain rehabilitation, falls management, end-of-life care)

A full summary chart of the extracted details for the selected studies can be found in the Supplementary Material.

Datasets and methodologies

Every study utilised patient records in some format via either electronic health systems, registries, logbooks

or by linking relevant databases of these kinds ($n=190$, 100.0%). The size of datasets varied widely though the mean and standard deviation indicated a heavy negative skew ($\bar{x}=16273.80851$, $SD=82069.15373$). The median therefore as a more appropriate measure was calculated to be 315 (interquartile range=2098.74). The smallest dataset contained 10 records, whereas the largest was 959,100.

The variables collected and reported differed though some standard fields of patient age and gender emerged. Many studies included forms of outcome measures relevant to the clinical area, however even when clinical areas were the same, there was not always standardisation. For example, ten studies specifically explored back pain [55, 68, 76, 84, 91, 95, 97, 100, 101, 113] and many included a measure of pain severity, however the way this was measured varied study to study. Some made use of visual analogue scales [70], others used formal tools such as the Modified Low Back Pain Disability Questionnaire (MDQ) [55, 101] or less formal approaches such a self-report of pain improvement [84].

Most studies were purely quantitative ($n=179$, 94.7%) and only one study’s main investigation comprised a qualitative analysis of textual components of medical records (though they did utilise quantitative data to describe the patient cohort) [175]. Several ($n=7$, 3.2%)

adopted a mixed-methods approach [127, 174, 176, 177, 191, 230], with the qualitative components also being analyses of textual components of patient records. A small number of studies were predominantly quantitative but incorporated qualitative elements which were not from RCD, such as questionnaires ($n=2$, 1.1%).

Social justice

A total of 27 studies (14.2%) had some degree of association with elements of social justice, and some addressed multiple components of this. Of the 27 studies, only 15 (55.6%) were reported as *centring* social justice in their study. Table 4 provides the distribution of this mapping and corresponding citations.

Of those studies which centred on issues related to social justice, they were largely linked to one of three themes: (1) *equal access to healthcare* ($n=7$); (2) *marginalised populations or research from post-colonial contexts* ($n=4$), or (3) *human rights* more broadly ($n=3$, which included consideration of the rights of people with disabilities and victims of sex trafficking). The studies that explored health inequity mostly looked at a range of social determinants of health and how this was related to health care access, though others were more focused on specific aspects such as equity arising from discrimination due to disability or ethnicity (particularly Aboriginal peoples in Australia). The singular study which centred on intersectionality focused on men who faced multiple levels of disadvantage and their use of mental health services.

It was noted that many of the studies collected data on relevant variables for exploring issues related to social justice including social determinants of health. Socio-economic status, deprivation or educational level was evaluated in 30 studies (15.8%), ethnicity or race was reported on in 25 studies (12.6%), and language spoken in 8 studies (5.7%). However, only very few of these studies operationalised these variables in a way that tackled

questions pertinent to social justice. Furthermore, only 6 studies situated themselves as bridging a research-to-practice gap which also focused on an element of social justice [93, 128, 145, 161, 209, 219]. These have been summarised in Table 5 to illustrate the nuances of this particular subset of studies.

Narrative summary of results

This analysis has unveiled the extent to which allied health fields are utilising RCD which is substantiated by the volume of studies included in this review ($n=190$). Whilst there is indicative evidence of the use of these data sources for research across the professions, physiotherapy predominates, and biomedical sciences is significantly underrepresented. Though, it is important this is reflected upon in the context of the relative sizes of the profession (for example, the physiotherapy workforce is substantially larger than the other included professions, at least in the UK [244]) and their fit with more traditional research approaches, where for example, biomedical sciences may be more typically core to pharmaceutical or clinical trials.

A significant finding from this review pertains to the volume of clinician-led research, comprising 44.2% ($n=84$) of all articles retrieved, including 5.8% ($n=11$) which were sole-authored. Yet, most clinician-led studies were collaborative and included a team of either fellow clinicians ($n=24$, 12.6%), academics ($n=38$, 20%) or a mixed team of clinicians and academics ($n=37$, 19.5%). Several publications were produced at least in part by authors employed by professional societies ($n=9$, 4.7%). Only 16 studies (8.4%) were produced by purely academic authors. There were few qualitative studies, though textual elements of patient notes were used for analysis in this way in some articles.

Studies addressing aspects of social justice were limited, and there was little geographic diversity in the publishing institution. Many of the studies come from

Table 4 Studies exploring elements of social justice

Degree of focus	Social justice		Health inequities		Under-represented groups		Intersectionality	
	n	%	n	%	n	%	n	%
Central	14 (83,92,93,118,126–128,130,135,145,161,174,209,219)	7.4%	9 (83,93,118,126–128,130,135,219)	4.7%	8 (83,93,118,126–128,174,221)	4.2%	1 (118)	0.5%
Secondary	5 (84,121,122,182,217)	2.6%	1 (69)	0.5%	3 (130,135,219)	1.6%	0	0.0%
Mention	4 (69,79,134,144)	2.1%	6 (92,121,122,182,209,244)	3.2%	3 (84,169,209)	1.6%	1 (207)	0.5%
Total	23	12.1%	16	8.4%	14	7.4%	2	1.1%

Table 4 The degree to which studies utilising RCD included in this review addressed elements of social justice

Table 5 A summary of six studies addressing social justice and research to practice gaps

Reference	Aim of study	Social justice aspect	Research to practice aspect
128	Evaluation of a service for people with a disability and a mental health difficulty	In the service, both the service user and therapist had a disability, mitigating barriers for people with a disability to accessing high quality care.	Disability studies provide a wealth of evidence to support the value of uniquely disability-related shared experiences in therapeutic relationships, but clinical research and practice ignores, and fails to implement this.
161	Evaluation of a model of trauma care provided across regions near the Iran-Iraq border.	Research about what works in trauma care for low- income, war-torn countries prone to complex mass casualties, such as Iraq is essential.	The existing evidence base for trauma care is problematic as there is limited transferability of much paramedical sciences research which is related to models applied in high-income, mostly Western contexts.
219	Exploration of inequalities in access to public neurodevelopmental services.	Analyses on comparisons of service access between families from mainstream and typically marginalised communities (e.g. culturally or linguistically diverse, or socio-economically disadvantaged).	There is an identified challenge of applying best practice guidelines for providing neurodevelopment services in the 'real world'.
93	Examination of the provision of physiotherapy for children or Australian First Nations heritage with bronchiectasis.	Australian First Nation Children experience the highest rates of bronchiectasis globally, which is associated with a 20-year mortality gap, arising from sub-optimal detection and management.	Best-practice guidance exists, though none of the research focuses on this specific population. The authors highlight that research about <i>access</i> to services is lacking.
145	Evaluation of the effectiveness of narrative exposure therapy for female victims of trafficking.	Victims of human trafficking are vulnerable to post-traumatic stress-disorder (PTSD), with specific stressors related to migration status and socio-political contexts, requiring specialist intervention.	Engagements of trafficking victims in trials is challenging and evidence is lacking on how to support this group. Narrative Exposure Therapy (NET) is one intervention developed for use in countries with insecurity and high risk of repeat trauma, but it has not been evidenced in this population yet.
209	Investigation of characteristics influencing the amount of therapy provided in stroke care.	There is substantial variation in the amount of therapy that people receive post-stroke, which may be due to patient factors (such as ethnicity) and organisational factors.	Best practice guidance recommends set amounts of therapy following stroke, but this is rarely implemented, which previous research has highlighted.

Table 5 A summary of the six identified studies addressing social justice and research to practice gaps, including the study aim and short description of each component

Central Europe or the Americas ($n=141$, 74.2%), and these represent 70.4% ($n=19$) of the articles addressing social justice. There is a slightly higher rate of social-justice focused literature emerging from outside these areas compared to within, which includes Eastern European countries (Turkey), Middle Eastern countries (United Arab Emirates, Israel, Saudi Arabia, Iran, Iraq), Asia more broadly (China, Japan, Pakistan, Thailand), Africa (Nigeria) as well as Pacific Islands (Papua New Guinea) and Australia and New Zealand. According to data extracted in this review, for every 100 papers published in Central Europe or the Americas, 13 address social justice, whereas in areas outside of this, it would be 16 studies. Many more studies had the potential to tackle questions around social justice based on the types of data that they were collecting but did not do so.

Discussion

This scoping review has revealed the extent to which allied health professions are utilising RCD, which appears to be embraced most in the field of physiotherapy, though is evidently applied by a range of professions. Notably, the studies were very often produced by a diverse team of practitioners in the specific health fields, along with academics. Perhaps reflective of this, some of these studies were explicitly situated in the context of utilisation of RCD to address an identified research-to-practice or implementation gap, though many studies took a narrower focus to address specific local concerns (such as managing waiting lists). Regardless of the context their study was presented in, most related to exploring the quality of services, patient profiles and intervention processes or outcomes. Despite vast volumes of relevant data often being collected, very few studies utilised it to tackle issues pertaining to social justice. However, those that did largely explored factors related to equity of access to health, and health inequalities more broadly. Very rarely was an intersectional lens taken in analysis, which was only identified in one study in this review.

The discussion herein focuses on the application of our findings to produce three recommendations for the consideration of scholarly and clinical communities.

Recommendation 1: Greater efforts to leverage RWD for research need to be made to unlock new knowledge, which is uniquely placed to complement, challenge, provide context for and - where needed - stand in the absence of traditional clinical research.

Whilst many studies were identified in this review, the volume and scale of RCD in healthcare should be considered to provide greater perspective on the actual extent to which it is leveraged. It is relevant to consider that no date range was applied to our search, thus the 190 studies

examined represents the entirety of the scholarly literature retrieved on this topic. Notwithstanding the finding that most of these studies were based in England, there seems a radical underutilisation and/or under-reporting of RCD investigations globally. As such, our scoping review signals multiple avenues in which maximising RCD through research can enrich the evidence base.

Studies in our review often strived to address a research to practice or implementation gap, and a subset of these specifically aimed to describe what 'routine' or 'usual' care was in their field, by tapping into their patient data. In many allied health fields, 'real world' clinical practice is often eclectic and complex with little consensus around what treatments precisely comprise [245, 246]. The value of unpacking this is threefold, since it can be used: (i) by clinicians to understand common approaches to treatment and guide quality of care, (ii) by clinicians and researchers to compare effectiveness of approaches and (iii) by researchers who can grasp better insight into the often-applied 'catch-all' of 'usual care' in study control arms, and thus improve the rigour of their trials. This role of RCD is also starting to be explored via AI [247].

Furthermore, the focus of studies identified in this review on describing patient profiles similarly spoke to the need to understand 'real' populations and the effects of treatments on them. This can similarly serve several purposes for health care providers to better understand who they are (and aren't) treating, which is particularly valuable for exploring potential health inequalities (though the studies that did this for such a purpose were minimal in this review). Similarly, understanding 'real world' clinical populations and trends in these can support research trials in their sampling strategies and participant recruitment, and can be used to challenge the suitability of evidence-based interventions to real world settings and populations. Facilitated understanding of patient cohorts through AI-assisted data mining of RCD is beginning to emerge in the literature [248], indeed some of the studies included in the review were centred on looking at change over time or the impact of a change imposed on services, which could be leveraged in this way.

Similarly, though the number of studies exploring issues related to social justice was small, those that did signalled very valuable findings and recommendations for both practice and research, and thus can serve as exemplars of how RCD can and should be leveraged for these important investigations. An emergent notion from our analysis was the production of RCD studies from lower income countries, where the authors positioned their studies specifically targeting gaps in research arising from an absence or severe lack of research conducted in their context or on their population, critiquing the

appropriateness of largely Western-produced knowledge about health and healthcare. This finding especially illustrates the unique value of RWD studies in a global health context, bringing into focus the tacit knowledge of local actors and local realities, contributing to the decolonisation of health [249].

However, whilst leveraging RCD for these purposes clearly has benefits, this review does reveal a need for greater standardisation of the ways in which data is recorded. Standardisation of treatment outcome measures and the ways treatments are described would maximise data linkage opportunities and enhance the added-value RCD offers to research. Data relevance, completeness and quality issues were commonly cited in the papers in this scoping review, and are often discussed as a significant limitation of leveraging RCD in other studies [250, 251]. The potential of RCD studies would be infinitely greater through the development and adoption of minimum data sets (MDSs) which establish data-collection protocols for clinical conditions or areas. Yet, for MDSs to really solve this issue, they need to be feasible for practitioners to adhere to in an every-day, busy clinical setting (for an example, see work by Harvey et al. involving a project to co-produce an MDS for aphasia, with researchers, clinicians and people with aphasia [252]). Doing so would enhance the quality of data and the potential for more meaningful analyses of RCD, which may also be assisted by AI powered analysis of electronic patient notes [253].

Recommendation 2: Practitioners should be positioned as the experts for asking the questions of RCD, to expose challenges in implementation of traditional evidence, unveil complexities of clinical practice, and create actionable evidence.

As highlighted through this scoping review, RCD investigations can often explicitly address a research translation gap and support evidence-based practice for on-the-ground clinicians. Recognising the unique perspectives of clinicians in driving RCD studies forward is imperative for the full potential of such studies to be met and their value to be recognised. Exemplified through the comparatively high proportion of clinician-led versus purely academically driven research in our review, practitioners are best-placed to identify the limitations and challenges in the existing evidence base or evidence-based guidance for implementation in the real-world and ask pertinent questions to be explored via their patient data. Many of the studies we reviewed utilised RCD to audit and scrutinise clinical practice compared with best-practice standards or guidelines, often revealing struggles with adhering to them. This ‘practice-based evidence’ created through

an RCD study provides important context and rationale for the reconsideration of service design on the one hand or inadequacies of guidelines on the other, as well as new avenues for research and ways to tackle health inequities [254]. This notion resonates with that of knowledge mobilisation, where insights from RCD provide reason for “*collective making*” of knowledge by on-the-ground actors [255]. Such knowledge may be more likely to be actioned in practice (compared with otherwise-distanced ‘research’) due to a greater sense of ownership and thus greater potential for implementation [255].

Often, studies included in this review tapped into their patient data to gather snapshots of their clinical services and generate real-time evidence to inform practice when needed and examine the impact of change. For example, several studies included in this review produced insights to examine the impact of COVID-19 on their health care services and patient outcomes, as well as new conditions where evidence is lacking but very much needed, such as Long Covid [167]. These studies illustrate the usefulness of RCD in unprecedented situations, which cannot always ‘wait’ for large scale trials or longitudinal studies to create required evidence. Echoing the points in the previous section, this novel intelligence can also be highly valuable for planning future clinical studies.

Respecting and empowering allied health practitioners to lead research, which can be in collaboration with academic researchers, has emerged as a strategic focus particularly within the UK (for example, in 2022, NHS England published an Allied Health Professions Research and Innovation Strategy [256]), a move which is supported by the findings of our review highlighting the value of clinician-led and prioritised research in closing research to practice gaps via RCD studies. Scholars are beginning to advocate for a shift towards welcoming practitioners into ‘academic spaces’ to specifically address research translation and evidence-based practice, which is also recognised by clinicians themselves [257, 258]. Moreover, there is growing evidence that clinician engagement in research can directly benefit patient outcomes [259]. Recent advances in supporting allied health practitioners to develop the skills and capabilities have been made, in the UK [260], though given the extent of reported challenges and barriers for on-the-ground allied health clinicians to engage in research [261, 262], it is yet to be seen if this concerted effort overcomes them. Our scoping review adds further impetus for the need for specific strategies to embed research capability in clinical roles, showcasing the unique value of practitioner-led research, especially utilising RCD.

Recommendation 3: Challenge received wisdom, traditional hierarchies of evidence and research paradigms and expand the academic gaze to value RCD studies (of any magnitude), especially for their role in exploring research applicability, translation and exposing issues related to social justice.

One consideration that may partly explain the discrepancy between the extent to which RCD research has been published – as identified in this review – and its potential to contribute to the evidence base and tackle issues pertaining to social justice is the often-narrow perception of what constitutes ‘high quality research’. Whilst it has been remodelled, redeveloped and reclassified over time, the classic hierarchy of evidence – its original conceptualisation of which is often attributed to pioneer of ‘evidence-based medicine’, David Sackett [263] – places non-controlled and observational studies, evidence generated by single-sites, single-cases and practice-based evidence including studies utilising RCD such as audits, or service evaluations, at the bottom of the hierarchy, signalling the limitations of their rigour, and consequently indicate caution about their appropriateness to inform practice [263]. Supportive of this traditional paradigm, significant warnings and many valid concerns have been voiced about Big Data health research (typically making use of RCD) due to the inherent biases arising at the level of data collection, including those that arise from practitioners’ and providers’ own biases as well as challenges in controlling variables and eliminating ‘noise’ [6, 167, 250, 251]. Despite this cautionary approach, there have been substantial efforts by major health care stakeholders to promote large scale routine data collection for the production of real-world evidence [3–5], investments by AI companies to exploit it, and medical studies to operationalise it. As such, there remains a mismatch in what forms of research have been traditionally perceived of as high quality and value (and those which are not), and what the contemporary priorities for health care are. RCD studies are thus situated amidst this contention, indeed where real-world evidence is posited as a “disruptive force” [264].

Furthermore, examining the classical hierarchy of evidence and research paradigms through the lens of social justice unveils the likelihood that traditional research produces bodies of evidence which are significantly biased (towards certain populations due to underrepresentation of marginalised groups), inappropriate (by centring Western models of medicine and perpetuating barriers to healthcare) and which simply fail to be useful for the global majority (by largely evaluating service delivery and provision that is unobtainable and unsuitable in middle and low income countries). Judgement

on research *quality*, as considered through classic paradigms, is thereby challenged. Yet, even RCD studies are not without risk of creating evidence that could reproduce structural and societal injustices – which may be perpetuated by AI especially [265–267] – and it is imperative to adopt a critical lens when reporting findings from such studies. The ‘*QuantCrit*’ framework carefully sets out recommendations for how quantitative data, such as Big Data in health, can be operationalised for social justice; an example being the imperative of when examining the variable of ‘race’ to “read ‘racism’”, thereby highlighting an “*operation of racism*” rather than ‘race’ being “*a cause in its own right*” [268]. There is a need therefore to carefully examine *how* data is utilised in this way (whether by AI or else) and scrutinise the forces at play which may skew findings at all levels of data collection, analysis and importantly, interpretation. Whilst clearly not the sole answer to tackling these issues and avoiding “*data chauvinism*” [25], we argue that RCD studies have the potential to re-orient and re-balance the evidence base in certain ways to mitigate the perpetuation of social injustices regarding health and health care.

The conflicting schools of thought regarding utilisation of RCD need to be remedied through a reconceptualization of the ‘hierarchy’ of evidence [269]. Resonating with recent *Nature* ponderings [57], emerging calls to decolonise health research [249, 270] and long-standing recommendations from the WHO commission [271], our scoping review supports the need for a departure from the orthodox (and colonial) conceptions of research *quality* and *value* and argue for a shift towards accepting a more flexible and dynamic relationship between and across diverse research approaches, which acknowledges the unique and powerful place that RCD studies and practice-based research (of any magnitude) can occupy in: (a) the production and translation of research into practice (b) improvements to clinical trials and (c) tackling social justice. Widening our definition of research *quality* and understanding of research *value*, and positioning RCD within this, can ultimately develop and enhance the evidence-base and optimise care for *all* patients.

Limitations

Whilst this scoping review has been expansive, it is nonetheless limited by its conservative search strategy which was largely developed pragmatically to ensure successful and timely completion of the study. However, it is also possible that studies were missed given our selective database choices and the skew in expertise in the team despite attempts to bring in targeted collaborators. During the screening process of the articles that were

retrieved, it is possible that the researchers' biases and naivete of certain clinical topics or professionals' scope of practice meant that papers were incorrectly excluded. For example, the identification of only one study in the biomedical sciences profession could reflect that this profession is perhaps more removed from the clinical expertise within the team and other studies relevant to this field may have been excluded.

Additionally, our data extraction framework is somewhat reductionist in the way in which it aims to capture complex topics such as social justice, which is subsequently reflected in our synthesis. However, by identifying and mapping the studies in this way, we hope it signals potential future avenues for further exploration of the work done in these areas. For example, it is likely that a narrative literature review may be well suited to exploring the studies that aimed to address issues of social justice in more detail. It is also important to note and reflect on the positionality and location of the research team undertaking this work (all are White women employed by an academic institution in England), from a greatly privileged perspective. Our discourse on social justice, and approach to this research, is thereby highly likely to be influenced by this and we are aware there is an absence of voice and perspective from people who have experienced greater social injustices who may bring a more critical and meaningful lens to the review.

Conclusions

This scoping review has underscored that there is much potential in leveraging RCD to bridge challenges in evidence-based practice, as well as adding context to traditional research methodologies, and can address pertinent social issues such as health inequities, providing information on client groups with complex, rare conditions who are frequently excluded from such studies, and interrogating injustices in allied health fields. However, to date, there is a relatively low representation of these studies in the literature. Our synthesis underpins three recommendations for consideration by academics, practitioners, and the applied health scholarly community more broadly, which advocate for greater: recognition and use of health data, enablement of practitioner-led research and consideration of diverse research forms and their dynamic interplay. We urge adoption of a 'Quant-Crit' approach [268] to doing so, where subsequently the evidence-base underpinning clinical practice can be expanded, enriched, and fit for purpose to enable equitable living and health for all. Future research exploring standardisation of data collection across providers and patients and on effective strategies to enhance clinician-researcher capability will be useful to drive this agenda forward. Furthermore, an examination of approaches to

data collection and analysis which minimise the risk of reproducing social injustices – with and without AI- and greater consideration of long-standing research paradigms would be central to advancing our understanding of how RCD can be operationalised effectively to further the pursuit of social justice.

Abbreviations

RCD	Routinely collected data
RWD	Real world data
OSF	Open Science Framework
AI	Artificial Intelligence
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12874-025-02466-9>.

Supplementary Material 1.

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Authors' contributions

KC was responsible for project conception and methodological design, lead researcher in the screening and extraction processes, undertook data analysis, and developed the first draft of the manuscript. AC contributed to the methodological design, article screening process and data extraction, and editing of the final manuscript. AP contributed to the methodological design, article screening process and data extraction, and editing of the final manuscript. PE contributed to the methodological design and editing of the final manuscript.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate

As a literature review, ethical approval was not required. The study had no participants and thus did not require consent.

Consent for publication

This literature review did not include any participants who needed to consent for publication. All authors consent to publication.

Competing interests

The authors declare no competing interests.

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